

# Public Involvement in Research:

## Ways of Building Partnerships

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### Contents

What is public involvement in research? .....	1
Which stage of the research cycle? .....	2
Who says? .....	2
Funding .....	7
Attitudes .....	8
Examples of involvement in lab research .....	9
What can you do now? .....	10
Resources .....	11

### What is public involvement in research?

The National Health and Medical Research Council defines involvement as:

**“research being carried out with or by consumers and community members rather than to, about or for them.”<sup>1</sup>**

But there’s a word in there that I don’t use. ‘Consumer’. This word for me does not imply an equal partnership. I prefer saying ‘the public’ or even ‘people’. The Health Research Authority in England came up with what I think is the best description of ‘the public’:

“When we use this term public means patients, potential patients or members of the public including those with known genetic dispositions, carers and people who use health and social care services as well as people from organisations that represent people who use health and social care services.”<sup>2</sup>

It is important to explore these different terms. Do you really need ‘patient’ involvement, or just someone to check it is in plain English – or do you need someone with a very specific experience or condition to help inform your work. It is very important to reflect on the tasks that you will be asking people to do – and what skills, experience or knowledge that person might require. In addition, it’s very important to always consider what support they might need. This might be learning and development, financial or emotional support – perhaps a buddy or mentor.

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<sup>1</sup> <https://consultations.nhmrc.gov.au/files/consultations/drafts/draftconsstatementconsultationversion140807.pdf>

<sup>2</sup> <http://www.hra.nhs.uk/documents/2013/10/hra-public-involvement-strategy-circulation-september-2013.pdf>

## Which stage of the research cycle?

The public can be involved at every stage of the research cycle, from identifying topics, prioritisation, to funding, designing trials (improving recruitment), analysing data, dissemination and even translation.

Stage	Why involve the public	How	Example
Identifying and prioritising	Involving the public in helping to identify and prioritise research allows them to influence what will be researched and lets researchers check that research priorities are the same as those of people who have the conditions being researched or who use relevant services.	<p>Use a mixture of face to face and online tools to facilitate discussions with existing reference groups and networks.</p> <p>This can include inviting the public to an event or researchers attending public and patient forums and events.</p>	The James Lind Alliance facilitates Priority Setting Partnerships. These partnerships bring patients, carers and clinicians together to identify and prioritise the treatment uncertainties which they agree are the most important for research.
Funding or commissioning	Many funding organisations now involve members of the public in commissioning research. This gives a broader perspective to the review process, by considering the issues that are important from a public perspective.	<ul style="list-style-type: none"><li>• Involve members of the public in reviewing research proposals</li><li>• Have a members of the public on research commissioning panels or boards</li><li>• Research grant applications</li><li>• Organisations representing groups or conditions commissioning research.</li></ul>	After asking people affected by multiple sclerosis, the MS Society decided to fund research into improving the day-to-day lives of the people it affects, as well as biomedical research.

Stage	Why involve the public	How	Example
Designing and managing	Involving members of the public in the design of research helps to ensure that the research is relevant to the needs of people, helps ensure the research question and outcomes are clear and ensures the research method has thought about the needs of anybody participating in the research.	Involve the public in: <ul style="list-style-type: none"> <li>• Reviewing proposals and commenting on any potential difficulties in the design</li> <li>• Developing research tools, information such as questionnaires, patient information sheets and consent forms</li> <li>• Monitoring and managing the research process</li> <li>• The selection process of staff and researchers</li> </ul>	The 'Workplace Impact of Supported Employment Study' involved service users in the design of study through a local group. The purpose was to investigate the impact of Individual Placement and Support in a mental health catchment area.
Undertaking	Involving members of the public in undertaking research can mean that research is carried out by people with a personal experience of the area of research or with relevant knowledge of a particular culture.	Involve the public in: <ul style="list-style-type: none"> <li>• Gathering and reviewing documentary evidence</li> <li>• Carrying out interviews and running focus groups</li> <li>• Developing research tools and information</li> <li>• Analysing and interpreting the data or results of research.</li> </ul>	The Macmillan Listening Study trained people affected by cancer to carry out research to identify the cancer research priorities of people affected by cancer
Analysing and interpreting	Why: Publishing linked data and results in the public domain allows others to analyse any findings and facilitates a range of people to give their time, scrutiny and perspective to the research	Involve the public in: <ul style="list-style-type: none"> <li>• Interpreting and commenting on results</li> <li>• Analysing publicly available open data</li> </ul>	The University Of Western Australia founded a programme to support researchers, consumers and the community to work in partnership to make decisions about research development using linked data.

Stage	Why involve the public	How	Example
Disseminating	Why: Dissemination is critical is the knowledge gained from the research is to have an impact. Good dissemination can also help identify the need for further research in a particular area.	Involve the public in: <ul style="list-style-type: none"> <li>• Developing the dissemination plan</li> <li>• Summarising the research findings in clear and accessible ways</li> <li>• Presenting at conferences, speaking to patients, support groups and service providers</li> <li>• Publication in open access peer-reviewed scientific journals</li> <li>• Publishing on websites, writing to journalists, creating leaflets for waiting rooms or community centres.</li> </ul>	The Eve Appeal sent a letter to everyone who took part in the UKCTOCS screening trial and offered them the chance to continue to receive updates.
Implementing	Why: Members of the public involved in research are often passionate to ensure that action happens as a result of the research and are often able to establish relationships with key agencies and policy makers.	Work in partnership to plan the implementation as early as possible.	Example: Service user researchers and a nursing researcher co-delivered training in therapeutic interventions to staff teams in a mental health trust (St George's, University of London)
Evaluating impact	By evaluating the impact of research and public involvement in research, you can help to build an evidence base and let others know about what worked well and what could be improved.	Involve the public in: <ul style="list-style-type: none"> <li>• How you are going to monitor and evaluate the impact of the research, and the public involvement in the research!</li> <li>• Writing up (and publishing) an evaluation of the public involvement itself!</li> </ul>	The UK Clinical Research Collaboration published a report of a project to evaluate patient and public involvement in research.

This table is adapted from the resource 'Building Research Partnerships' – which can be downloaded for free here:

[macmillan.org.uk/researchlearning](http://macmillan.org.uk/researchlearning)

In addition, INVOLVE have a page of more resources which describe how you can involve people at each stage of the research cycle:

<http://www.invo.org.uk/posttypesresource/where-and-how-to-involve-in-the-research-cycle/>

# Who says?

The National Health and Medical Research Council “Revised Statement on Consumer and Community Involvement in Health and Medical Research statement” says:

**“Active involvement of consumers and community members in health and medical research benefits the quality and direction of research.** The vision for the Statement is: Consumers, community members and researchers will work in partnerships based on understanding, respect and shared commitment to research that will improve the health of all Australians. Consumer and community involvement is about research being carried out with or by consumers and community members rather than to, about or for them. It includes consumers and community members working with research funders to prioritise research, being involved in grant funding processes and providing advice as members of project steering groups. This is distinct from people who are the participants in research projects”<sup>3</sup>

A recent review of public involvement by the National Institute for Health Research recommends that ‘relevance’ be one of the three measures of success of future public involvement in health and social care research.<sup>4</sup>

What is relevance? **‘questions that reflect the interests and needs of patients, carers and clinicians’<sup>5</sup>**

A recent paper about involvement concluded that best-practice is to “Involve early - Patient input is often most impactful in the project formation phase. Researchers tend to have a focus on scientific questions and less on the wider context of disease. Patients can bring the perspective of what it is like to live with a disease, or several diseases/comorbidities...By having patient organisations, and their patients, as funded partners, a patient perspective was incorporated into even the earliest drafts of the project proposal and work plan”<sup>6</sup>

A report from the National Institute for Health Research stated:

“public involvement in research has had a variety of impacts, including impact on the research (at all stages and levels), on the members of the public who were involved, on the researchers, on participants, on community organisations and the wider community. It has also influenced whether the results of research have been used to bring about change.”<sup>7</sup>

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<sup>3</sup> <http://consultations.nhmrc.gov.au/files/consultations/drafts/draftconsstatementconsultationversion140807.pdf>

<sup>4</sup> <http://www.nihr.ac.uk/get-involved/Extra%20Mile2.pdf>

<sup>5</sup> <http://www.researchinvolvement.com/content/1/1/2>

<sup>6</sup> <http://www.researchinvolvement.com/content/1/1/5>

<sup>7</sup> [http://www.invo.org.uk/wp-content/uploads/2011/11/Involve\\_Exploring\\_Impactfinal28.10.09.pdf](http://www.invo.org.uk/wp-content/uploads/2011/11/Involve_Exploring_Impactfinal28.10.09.pdf)

# Funding

There's a mismatch between research the public want done, and the research that gets funded.

I observed the James Lind Alliance<sup>8</sup> priority setting partnership with the MS society. Watching researchers and people affected by MS compare priorities was very interesting. As a result of this kind of work, the MS Society shifted their funding focus to curing and living with, rather than just curing.

A recent paper about the kind of research that gets funded stated that “In JLA PSPs, drugs accounted for only 18 % (23/126) of the treatments mentioned in priorities; in registered non-commercial trials, drugs accounted for 37 % (397/1069) of the treatments mentioned; and in registered commercial trials, drugs accounted for 86 % (689/798) of the treatments mentioned.”<sup>9</sup>

Just to pre-empt – this is not an attack on ‘blue sky’ research, or research that is done, even though we don’t know where it will lead. No one could have predicted the World Wide Web would emerge from CERN and who knows what new diagnostic techniques could emerge from the Large Hadron Collider – we need that kind of science.

Funders are also increasingly looking for examples of public involvement in grant applications. The National Institute for Health Research in England was the first large health research funder in the world to do this and it has set an example which is slowly being followed. For example, in Australia, Cancer Australia now ask for evidence of involvement in a grant application.

As one journal article recently stated: “Close and regular dialogue can help researchers to consider these outcomes and to prepare intelligible lay summaries of their research that will help generate realistic timescales and avoid exaggerated forecasts of impact. This, in turn, may assist in their applications for funding.”<sup>10</sup>

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<sup>8</sup> <http://www.lindalliance.org/>

<sup>9</sup> <http://www.researchinvolvement.com/content/1/1/2>

<sup>10</sup> <http://www.researchinvolvement.com/content/pdf/s40900-015-0002-y.pdf>

# Attitudes

Sometimes a change in attitude involves individuals reflecting on assumptions and actively challenging these.

Here are some helpful quotations that sum up some attitudes, taken from papers recently published in the new journal 'Research Involvement and Engagement':

- "There is a perception that patients either will not understand or would not be interested in the day-to-day operations of a research project. This often means that patients are given simplified and inaccurate explanations of how a project is progressing, what the challenges are and what the results mean. In reality, the more patients are involved in the day-to-day activities of the project, and the more they are informed about its progress, the more they can understand, contribute and positively impact."<sup>11</sup>
- Academic culture can often be very different from that of other spheres of work, and bringing lay representatives into the research arena helps to raise awareness of issues outside the academic culture box. This is particularly useful where researchers have moved through first and second degrees into doctorates and post-doctoral research in basic science. Lay members are more focussed on the practical aspects and outcomes of research and how it can affect patients and carers."<sup>12</sup>
- "The idea of patient involvement can be difficult for researchers as it does not adhere to the traditional "scientific method". The experiential knowledge of patients and the public, according to some, lacks the objectivity, verifiability, universality and rationality of scientific knowledge. However, it is now increasingly appreciated among researchers that patients' knowledge and experience is valuable for research and contributes to increasing the quality, relevance and appropriateness of research processes"<sup>13</sup>
- "A key feature of our model is that all research projects running through our facility are receiving involvement from a wide range of lay members. Individual lay members may get involved at a deeper level in specific projects, but they have broad involvement in everything that we do which means that on a monthly basis, there is always an opportunity for researchers and lay members to share opinions and ideas. This differs from many PPI models where individual projects are allocated one or two lay members whose involvement may go through peaks and troughs."<sup>14</sup>
- "Actually, it's surprising that it has taken us this long to focus on patient engagement because the results we have thus far are nothing short of astounding. If patient engagement were a drug, it would be the blockbuster drug of the century and malpractice not to use it." *Leonard Kish—Principal and Co-Founder of VivaPhi*<sup>15</sup>

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<sup>11</sup> <http://www.researchinvolvement.com/content/1/1/5>

<sup>12</sup> <http://www.researchinvolvement.com/content/pdf/s40900-015-0002-y.pdf>

<sup>13</sup> <http://www.researchinvolvement.com/content/1/1/4>

<sup>14</sup> <http://www.researchinvolvement.com/content/1/1/3>

<sup>15</sup> <http://www.researchinvolvement.com/content/1/1/4>



# Examples of involvement in lab research

Public involvement in lab research does require more imagination sometimes. Here examples of approaches, some of them very imaginative.

- **Learning and development for the public and patients.** [Building Research Partnerships](#) – shared learning for the public and researchers about public involvement and how to do it, is a model identified as best-practice in Europe. From these short one day events, relationships would develop and conversations would start. [Here is a poster](#) about the long term impact of this project. All resources are free and open access under Creative Commons.
- The [James Lind Alliance](#) is really worth looking into as an innovative model to help understand how the public can be involved at that essential stage of identifying topics and prioritising.
- I observed the Royal Brompton hospital run a '**Cafe scientific**' – it's an informal setting where scientists are invited to talk in laymen's terms about their work. There are many ways of doing it, but the events aim for an informal and friendly atmosphere, and are believed to improve the image of scientists and careers in science. Wikipedia says 'Cafe Scientifique aims to demystify scientific research for the general public and empower non-scientists to more comfortably and accurately assess science'. It's a space for people to ask and think – in all directions.
- **Research Buddies** - there are many variations on this, but essentially it is having members of the public, often people affected by a condition, paired with researchers helping motivate and enthuse them about their work. WEHI's system is leading edge work in Australia.
- **Groups and committees** - members of the public can be supported to be a part of all discussions – with learning and development and support (financial/emotional), everyone can be involved. The University of Western Australia has good examples of this<sup>16</sup>. There is a Consumer Advisory Panel at WEHI – get to know them (**contact Katya**).
- **Dissemination** - the public can help with disseminating results from lab research. The two previous projects could support lay people to be able to talk with researchers and about their research, and go to their community, online, or other settings to share results.
- **Interpretation of data** – Open access and linked-data. You can publish data for anyone to interpret - what more powerful way is there to share your research than to share your data with everyone? [Genes in space](#), [Eyewire](#), [Cell slider](#) – these are not within everyone's budget, but are hugely imaginative ways to harness the pattern spotting power of the brain - using our brains as a distributed network of computers.
- **Biobanking** – Having members of the public and donors involved at every level, including a 'lay steering committee....who are themselves donors' results in 'a proportion of the participants being engaged in dynamic consent' which is more practical. 17

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<sup>16</sup> <http://www.involvingpeopleinresearch.org.au/index.php/methods>

<sup>17</sup> <http://www.researchinvolvement.com/content/1/1/3>

# What can you do now?

- **Talk to people**
  - Find out what's going on - anyone doing anything similar?
  - Anyone want to work with you to start something yourself
- **Find support**
  - Does your organisation have funding for involvement? Could it need more?
  - Are there external organisations who can support, or individuals who can play a role in leading your organisation in this way of working?
  - Once you think you know what you want to do and where you need support, there are many people willing to give their time and expertise to projects, you only have to open your door and ask.
- **What do you want to do?**
  - Where do you want to involve people? Research prioritisation, research methodology review (e.g. human ethics applications), research reference group (e.g. review grants), research buddies, friends of the lab, public spokespersons for the importance/relevance of your research, helping disseminate.
  - What tasks will people have? Be specific and realistic, what are the commitments? Ask people for feedback on what you want them to do!
  - What support might they need? Learning and development, financial or emotional support – perhaps a buddy or mentor?
  - What type of involvement? Who might you unintentionally exclude? (committees, research buddies, friends of the lab, online, face to face, evening/day time? Paid/unpaid? Commitment short term or long term)
- **Make a plan:** How would your involvement be structured? (cross-organisational level, institutional level, department or lab, by project or with a collaborative tumour stream group)
- **What resources or support do you need?** Internal support from colleagues? External organisations or expertise for recruitment and training? Budget – see 'Budgeting for involvement'<sup>18</sup>
- **Do something, start early**
  - Even if it's a small, one-off event with some biscuits and a small group of people, you never know where it could lead.
- **Evaluate it, measure the impact.** Planning evaluation and impact assessment into your involvement ensures you can learn from experiences, improve and share your learning with others. It hopefully means we generate a larger evidence base for the benefits of involvement and best-practice.

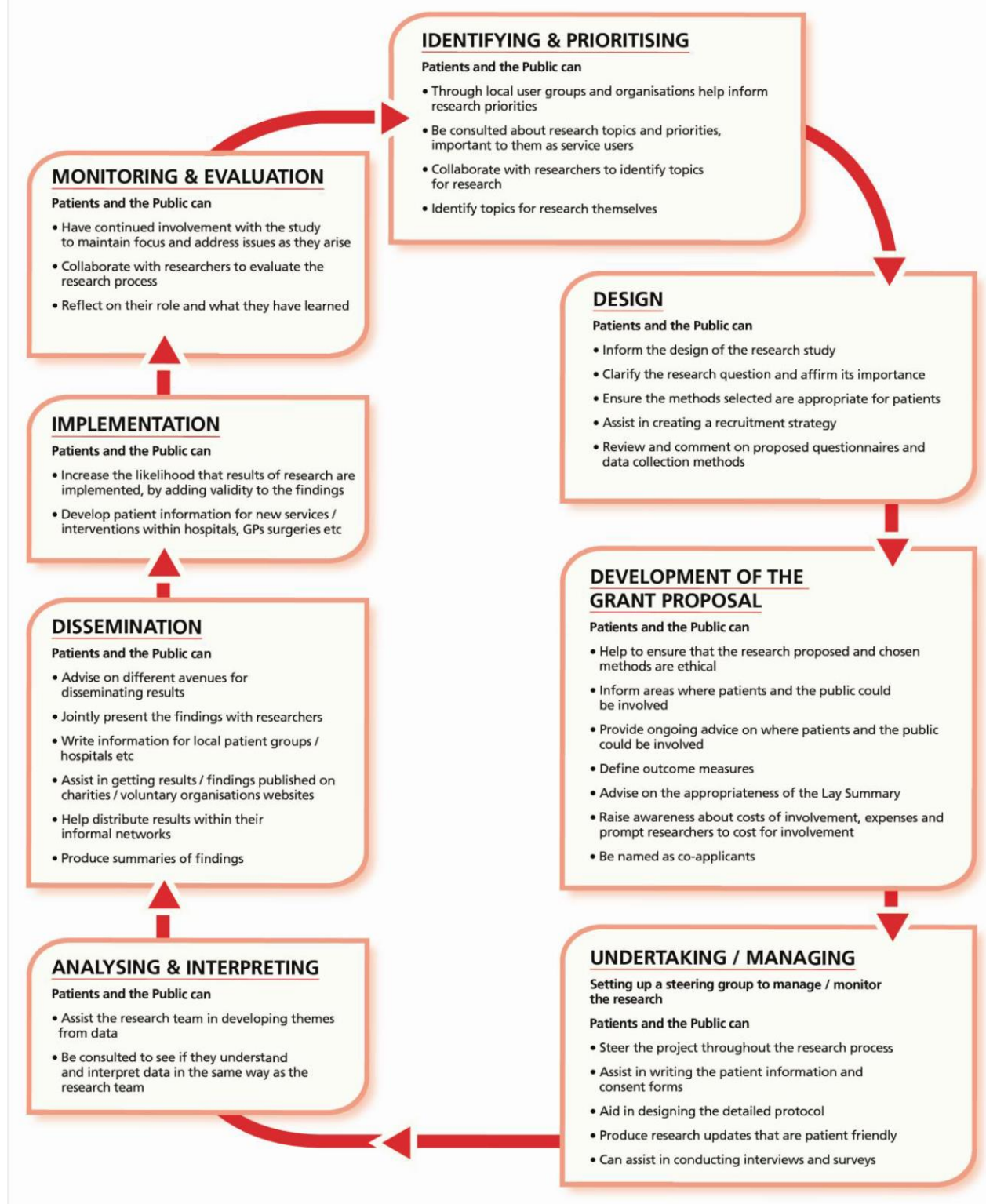
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<sup>18</sup> <http://www.invo.org.uk/posttypepublication/budgeting-for-involvement/>

# Resources

- Building Research Partnerships:
  - Here is a [poster](#) about the impact of involvement in research and shared learning events for the public and professionals.
  - [Here](#) is a report about the impact of the work
  - Here are the resources for free: [www.macmillan.org.uk/researchlearning](http://www.macmillan.org.uk/researchlearning) (page 64- 66 to help with planning involvement)
- [Here](#) is the NMHRC draft statement on 'Consumer and Community Involvement in Health and Medical Research'. [Here](#) is the Health Issues Centre response to this.
- The University of Western Australia's School of Population Health (the School) and Telethon Kids Institute's (the Institute) Consumer and Community Participation Program: <http://www.involvingpeopleinresearch.org.au/>
- INVOLVE resource about '[Budgeting for involvement](#)'
- National Institute for Health Research 2015 [report](#) about their public involvement strategy so far, and next steps.
- New journal – 'Research Involvement and Engagement' [www.researchinvolvement.com/](http://www.researchinvolvement.com/)

# How to incorporate patient and public involvement in the research process



From: [https://web.archive.org/web/20150731065101/http://www.rds-london.nihr.ac.uk/RDSLONDON/media/RDSContent/files/PDFs/RDS\\_PPI-Handbook\\_web\\_1.pdf](https://web.archive.org/web/20150731065101/http://www.rds-london.nihr.ac.uk/RDSLONDON/media/RDSContent/files/PDFs/RDS_PPI-Handbook_web_1.pdf)

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